DISCUSSION*

DAVID ROGERS, M.D.
University Professor of Medicine
Cornell University Medical School
New York, New York

I want to express my pleasure at being invited to participate in this tribute to David Axelrod, and to extend my welcome and thanks to Bill Roper, a good friend and thoughtful physician, for providing us with his perspective on the HIV epidemic.

First a few words about David Axelrod. To put it simply, he was a class act. Brilliant, tough, enormously hard-working, and committed to assuring quality health care for all—particularly the less fortunate in our society. We worked closely and intensely together for four years building programs in AIDS that I will speak of again somewhat later. I miss him enormously.

I feel fortunate in knowing his successor, Mark Chassin, who is with us today. He is also brilliant, hard-working, and he has a similar value system. He has some big shoes to fill and we will all help him.

These are troubling times for anyone concerned about the health of the public. In New York City, emergency rooms and intensive-care units are overflowing. The percentage of emergency room patients admitted for inpatient care has become much too high, exacting enormous stresses on our hospitals. There have been dramatic increases in tuberculosis, sexually-transmitted diseases, and drug exposed births. Medicaid costs are skyrocketing. Health care personnel are overstressed and in short supply. Draconian cuts in financing are wrecking day care services, pediatric dentistry, maternal health services, screening for lead poisoning, and public health education. Indeed, we seem to be dismantling the very foundations of preventive health care.

And now, superimposed on this bleak portrait is the major health crisis of our times: AIDS and HIV infection. We are in the midst of a public health disaster of monumental proportions—a disaster much more tragic because of its preventability.

---

* Presented as part of a symposium, *Dr. David Axelrod and the Health of the Public: Looking Ahead,* cosponsored by the New York State Department of Health, the New York Academy of Medicine, and the Josiah Macy, Jr. Foundation October 23, 1991.

Serving as chairman of the New York State AIDS Advisory Council and vice-chair of the National Commission on AIDS, I see all too painfully those steps that are needed to control this epidemic on the one hand, and, on the other, a singular lack of national will to take those steps.

Many of you may know my own feelings about our national response to AIDS. Put bluntly, I think it has been tragically slow, frequently short-sighted, and often callous and stingy. We have not done well. Let me hasten to add that those problems rest in Washington, D.C., not in Atlanta, Georgia.

But, as I have watched the relentless march of this human disaster, I have been increasingly troubled by the silence at high levels. I cannot simply fault the public for its apparent indifference or misdirected fears. They have not really been told of the magnitude of the disaster or how we must act to cope with it effectively.

The National Commission on AIDS has reported within the past month on what we see as the serious failings of Washington to set the tone and direction for Americans. In essence we've said: "Mr. President, you are not leading this country. We need your leadership, we need your decisive call to action for the American people, to Congress, and to your Administration to move appropriately to control this epidemic."

The Commission has kept its recommendations simple, because what is needed to control the epidemic is not complex. We need frank and culturally appropriate prevention services directed particularly toward our youth—our failings here approach the criminal. We need enough outreach and early treatment to care for all those who are HIV infected who need them. We need enough drug treatment slots to take care of all those who desire it, and sterile cleaning and injection equipment to protect those who don't. We need to take advantage of the highly-skilled community-based programs that are providing education and support services. And we need to treat all sick people decently and non-judgmentally. The amount of suffering is enormous and our absence of caring contributes to it.

These are simple steps that could have been taken long ago if we had gutsy, compassionate leaders in Washington.

Here in New York State I believe we're doing better. This is not to say that we couldn't and shouldn't do more.

But from my perspective there is a difference in both attitude and action in New York State when contrasted with the Washington scene.

Dr. David Axelrod is the major reason for that difference. We were fortunate to have had David at the helm of the Department of Health when the AIDS crisis hit. His intelligence and concerns for the sick made certain

that our actions were correct. His vision and courage enabled us to act decisively when many were unable to.

Simply put, because of David and what he put in place, New York has done better than any other state or nation in the world in dealing with AIDS. Let me give you a brief recounting of David Axelrod's legacy in HIV:

1) He established and fostered the AIDS Institute, now composed of an absolutely remarkable group of dedicated, ornery, pushy individuals who have been instrumental in shaping New York's response to AIDS.

2) He created an outstanding series of Designated AIDS Care Centers in hospitals across the state to serve as the keystones of treatment for people with HIV infection and AIDS.

3) He pushed the Medicaid and hospital funding systems to support a continuum of care for those with HIV infection more comprehensive than that found anywhere else in the U.S. or the world.

4) He invented and guided the AIDS Five-Year Plan, which has served as New York State's blueprint for action.

5) He created and supported a network of community-based HIV service programs and organizations which are now models for the nation.

6) He put in place the strongest confidentiality protections possible for persons living with HIV infection and AIDS.

7) He established a long-term care model to provide chronic care for persons with AIDS, an especially desperately needed resource in New York City.

8) He encouraged the creation of the AIDS Clinical Scholars program in HIV Primary Care and Substance Abuse.

The most remarkable aspect of this list of accomplishments is, of course, that these took place far in advance of any similar developments anywhere else. Many aspects of New York's program remain as yet unduplicated, although many states and the federal government are finally moving in these directions. These actions speak to David Axelrod's role as a pioneer, and as a public health visionary of first rank.

With the first decade of AIDS now past, David Axelrod's legacy sets a standard by which we must judge our actions in this second decade. I have thought of him frequently over the past several months as we have struggled with the issue of HIV-infected health care workers. It is an issue in which New York State has, I hope once again, suggested a path for others to follow.

When New York State issued guidelines on HIV-infected medical care personnel in January 1991, they represented a clear, rational dissection of a complicated policy issue tied up in misplaced public fears, lack of adequate

information, and heavy political pressure. Since that time nearly a year ago, all those complicating factors have increased in ferocity.

New York State in its guidelines issued two weeks ago chose the path that David first pointed to last January. I think that David's attitude toward the divergence of state and CDC guidelines would be close to mine; namely, that this is an issue about which reasonable people can disagree, but I believe that New York has chosen a better course.

I've spent a considerable amount of time over the last 10 months talking with Bill Roper, Jim Mason, and Lou Sullivan about the federal approach to this issue. In their basic initial thrust, the CDC recommendations represented, I believe, what they viewed as a frontline defense against the threat of more restrictive and punitive approaches. What was not well anticipated was what happened—Congress then scared the hell out of us all by putting forward the most restrictive and punitive recommendations possible.

To those who claim that politics and medicine don't mix, I say that they don't know their public health history very well. Any public health measure has a mix of governance, politics, and medicine. What we must be careful to avoid are those instances where the politics distort good medicine and good science.

The problem in this instance has been an unforeseen mix of fundamentalist reactionaryism with the truly tragic situation of Kimberly Bergalis, who has been so seriously misused by the Helmses and Dannenmeyers in our United States Congress.

When it comes to the health care setting, all would recognize that the potential for HIV transmission exists. How a public policy is framed to reduce the potential requires the adoption of a viewpoint. In this instance, New York has adopted a view that the risk is small, the policy implications broad, and the need to restrict narrow. CDC differs not in that view, but in how that view is translated into action.

The most striking thing about the guidelines put forth by both New York State and CDC are their broad similarities. Both rate the risk of transmission to be extremely low; both stress the critical importance of strict adherence to universal precautions and infection control procedures; both urge that health care workers know their HIV status; both call for a voluntary—not mandatory—approach to testing; and both recommend the establishment of review panels to evaluate infected workers who are performing invasive procedures.

But then we separate.

From here on, New York State's position could be characterized as acting on what we know about HIV transmission, while CDC's could be character-

ized as acting on what we don't know about HIV transmission. Both positions are rational and defensible at first blush. But when one examines the logical extensions of those positions, the need for an approach in New York State that is different from the CDC approach becomes quite evident.

The basic tenet of the New York State policy is that HIV infection alone does not justify limiting a health care worker's professional duties. New York proposes a set of uniform evaluation criteria—physical and mental competence, functional ability, compliance with established universal precautions, and infection control procedures—in addition to the nature of the procedure and HIV infection. This type of multifactorial process permits an informed and proper evaluation. I, in fact, propose that CDC adopt the New York evaluation model as one to be recommended nationwide.

The second area of divergence of CDC and New York State guidelines is disclosure of serostatus to patients by infected health care workers. CDC has recommended that in every instance where an infected worker performs an invasive procedure, the patient must be informed of the worker's serostatus. New York has quite specifically recommended the opposite; HIV-infected health care workers are not required to disclose their HIV status to patients or employers.

Why did New York choose this path? New York State is the epicenter of this epidemic; it has had more experience with the illness and more HIV-infected people and probably health care workers than anywhere else in the nation. In thinking out CDC's approach to its logical point of operation, New York concluded a number of things:

- First, the mandating disclosure at the end of a voluntary testing and review process would absolutely destroy that sensible plan. No health care worker will get involved in a process that results in the radical restriction of practice which inevitably follows disclosure. It will drive HIV-positive health care workers away from the care system.
- Second, that mandatory disclosure does absolutely nothing to ensure patient safety and leads to an assumption that workers who haven't tested positive are not infected and represent no risk. That's dead wrong. In contrast, universal precautions and infection control procedures do ensure patient safety.
- Third, telling patients that disclosure of the health care worker's HIV status is a safety mechanism is not only false, it inflates the importance of a worker's HIV status way out of proportion to any risk involved.
- Fourth, health care workers would be removed from their jobs, despite no established evidence of transmission from health care workers to

patients. This would diminish a precious commodity already in short supply in New York State. As a matter of fact, in the context of CDC's approach, HIV seroprevalence is already having an effect on our ability to recruit and retain both health care workers and health professions students.

- Last, and most devastating, these facets of the CDC guidelines send a dreadful message for health care professionals which reads: "Don't take care of anyone who is HIV positive, or who you even suspect is HIV positive, for you will lose your professional life."

I believe New York's approach is the right one. We have embraced the critical facets of the CDC guidelines, but have balanced it with a more pragmatic and science-based approach to meet our particular needs. The New York State policy is one that I believe would be useful in other states as well, and in fact we have already seen similar approaches from Michigan, San Francisco, and indications that others will go this way as well.

But what should we make of the quandary presented by the differences between CDC and New York State policies?

Here is an instance where Congress has been helpful. Thanks to the enlightened leadership of Henry Waxman and others, we have been presented with language which allows individual states to adopt guidelines which are "equivalent" to CDC's. States are permitted to construct approaches which are sensitive to their needs and consistent with the state-specific HIV approaches already in place. It seems to me that New York State has done just that.

Here, then, is an opportunity for CDC and New York State to come together in a way which results in public health benefit. CDC should, for all those reasons I have argued, judge New York State's policy to be equivalent, for it represents the proper course of action in New York State in this epidemic. It is a path which is informed by science, is protective of both patient and health care worker, is sensitive to the concerns of the public, is understanding of the reality of risks, and is cognizant of the need to act decisively.

Belinda Mason, my beloved fellow National Commission member who died of AIDS at 33 last month, said many quotable things. Let me close with two.

First, in a letter to the president designed to reduce the public fear of health professionals created by this whole misplaced health worker hassle she said: "Mr. President, doctors don't give people AIDS, they take care of them."

New York State's approach embraces this simple, but elegantly truthful concept.

But second, and on a broader note, she said: "America is in great danger—not of catching AIDS—but of losing its humanity. . . . In all of history there has never been a cure for that."

CDC and New York State now have the opportunity to come together in a way which has all the hallmarks of David Axelrod's and Belinda Mason's shared legacy: equal parts of intelligence, courage, and compassion; I urge them to do so.